

367.8:
A298/F49/
exec. sum.



312066 0273 8276 0

The Governor's Committee on ALZHEIMER'S DISEASE

Executive Summary



Michael S. Dukakis
Governor

Richard H. Rowland, Ph.D.
Executive Office of Elder Affairs

Lewis H. Weinstein
Committee Chairman

The Commonwealth of Massachusetts

1985



Digitized by the Internet Archive
in 2013

<http://archive.org/details/governorscommit00mass>

THE GOVERNOR'S COMMITTEE ON
ALZHEIMER'S DISEASE

EXECUTIVE SUMMARY



Sheila Clemon-Karp, Ph.D.
Staff Director

Lewis H. Weinstein
Committee Chair

THE COMMONWEALTH OF MASSACHUSETTS
1985

Richard H. Rowland, Ph.D.
Secretary, Executive Office
of Elder Affairs

Michael S. Dukakis
Governor

FOREWORD

Six months ago, on November 24, 1984, some sixty Massachusetts citizens were sworn in by Governor Michael S. Dukakis, who had appointed them members of the Governor's Committee on Alzheimer's Disease. The Committee had been established by Chapter 5 of the 1984 Resolves of the Legislature. The only charge to the Committee is general: to report "with recommendations for adequate care and support of the victims of this dread disease and their families." The caption is more specific; it states that the Resolve is "Relative to Making a Commitment to the Victims of the Debilitating Disease Known as Alzheimer's Disease, by Providing Respite Care for the Families of These Victims to Assist Them in Keeping These People in Their Own Homes and Avoiding or Postponing the Necessity of Placing Them in Nursing Homes." But the specificity of the caption does not limit the generality of the text of the Resolve. As our Supreme Judicial Court has said: "...[P]lain words in the text of a statute are not to be cut down by its title."

The Committee members constitute an extraordinary cross section of the Massachusetts community concerned with Alzheimer's Disease, individuals from all parts of the Commonwealth. From the Executive Branch came two members of the Governor's Cabinet: The Secretaries of the Executive Offices of Elder Affairs and of Human Services, and five Commissioners. From the Legislature came three Senators and three Representatives. From the medical, scientific and social service communities came leading physicians, teachers, and other experts in psychology, psychiatry, nursing, and social work. Among the members of the Committee were the President, two Vice-Presidents, the Executive Director and 17 other members of "Alzheimer's Disease and Related Disorders Association of Eastern Massachusetts" (ADRDA). The Committee also included a Suffolk County Probate and Family Court Justice, a Vice-President of Blue Cross/Blue Shield, the General Manager of WBZ-TV Channel 4, members of various groups and institutions providing care for Alzheimer's Disease patients and families in their homes, communities and institutions, private, charitable and public, all of them concerned with Alzheimer's patients.

Problems Facing the Committee

Our Committee faced countless problems. Some were obviously unanswerable by us: i.e., the cause of the disease or its cure or respite. No one disagreed with the need for early and correct medical diagnosis, nor with the fact that there was frequent lack of training and knowledge for such diagnosis by local medical practitioners. There were problems galore: the problem of the family not poor enough to obtain Medicaid, but unable to receive even partial reimbursement by Medicare, Blue Cross/Blue Shield, or private insurance; the family frequently spending \$30 to \$40 thousand a year for nursing homes, plus a similar additional amount where private nurses were necessary; the need for respite where an elderly spouse or breadwinner family member spends all non-working time with the Alzheimer's patient and needs some respite or replacement or rest or change

from the day and night support; the problem of the patient without family; the lack of specific numbers as to where Alzheimer's patients are and what care they are receiving; the need for demonstration projects, the need for a better understanding and evaluation of home, community, and institutional care (private, charitable and public); the need to know what other states and countries are doing; and the role of private insurance companies. Our first problem was how to find a way in which 60 individuals could complete in six months an enormous assignment.

Organization

It was clear from the outset that the Alzheimer's Committee, without delegation, could not function effectively as a 60-member Committee. At its first meeting, on December 3, 1984, the Committee decided to create an Executive Board to act between general Committee meetings, and seven Subcommittees: Current Programs, Research and Practice, Education, Finance and Insurance, Families, Community-Based Care and Institutional Care. Later, a Subcommittee on Legal Issues was established. A list of all the Executive Board members, the general Subcommittee Chairperson, and members are included in this report. All Chairpersons and all of the Legislative members were invited to attend Executive Board meetings. Dr. Sheila Clemon-Karp of the Executive Office of Elder Affairs was designated as our Staff Director, together with six members of that Office as staff for our Committee.

Public Hearings

The Committee, at its first meeting, determined to conduct a public hearing in the State House and another in Western Massachusetts; such hearings were held in Boston on February 8, 1985, and at Holyoke Community College two weeks later. Some 70 witnesses testified at the State House during a hearing that began at 10:00 a.m. and, without any break, ended at about 4:30 p.m. In Holyoke there were some 50 witnesses who testified from 10:00 a.m. to about 1:30 p.m. The hearings confirmed the recent statement by Dr. Lewis Thomas, a recognized medical authority, who stated that "Alzheimer's is the disease of this century" and "causes more damage to the family than any disease I can think of." There was overwhelming evidence that "Alzheimer's is an insidious disease; no illness is more terrifying and life altering than Alzheimer's."

The hearings not only raised issues and provided significant testimony, but included poignant reports of family tragedies: some cases of slow deterioration, others of rapid sweeping personality transformation and devastation, uncertainty, bitterness, grief, guilt, anxiety, fright, hopelessness, fixation, groping, particularly when the burden of caring for the patient falls on one individual, usually a spouse, child or sibling, in many cases the family breadwinner. Several witnesses had to cut short their testimony because of their inability to continue to talk; many were in tears.

We also heard from many witnesses of the need for information and education about the disease at all levels. Not only more information and education for the professionals and for the patient and the families, but also for the public generally, including answers to questions: "Who" are

the doctors? "Where are the institutions available to help and their addresses and telephone numbers?" "What kind of care is available?"

Our Committee heard sharp criticism of some physicians and high praise of others. There were repeated reference to "run-arounds", "wrong diagnoses", "no one knows", and above all, not knowing to whom to turn.

The hearings covered the panoramic sweep of the work of all of our Subcommittees; and the testimony, with written statements by the witnesses, became the subject of analysis, discussion and debate and of Subcommittee and Full Committee recommended action. The hearings also brought reports, frequently favorable, occasionally derogatory, about supplementary care in homes, day care centers, community-based agencies and institutions, public, charitable and private; claims of inadequate compensation for care workers and a wide variety of other subjects which concern Alzheimer's patients and their families.

And one question, asked in frustration, was searing. The question was rhetorical: "Why can't our doctors and scientists make a breakthrough for a cause or cure or respite from Alzheimer's? If they were able to discover 'L Dopa' for Parkinson's, why can't they find something that will alleviate Alzheimer's Disease symptoms, that will make life bearable?"

Committee and Subcommittee Action

Our Committee concluded early in its existence that it would not recommend state appropriations for medical or medically-related research in view of the grants by the federal government and foundations; that it would recommend appropriations only for home, respite and community-based care, for model or demonstration projects, not only in public institutions, but in private institutions, and for investigation and correlation, as described in the Recommendations in this report.

As each Subcommittee report became available in draft form (and there were several committees with over six draft reports), it was reviewed by the Executive Board, then re-submitted to other Subcommittee Chairpersons and then, as reports approached finality, by other Subcommittee members, until each member of the Full Committee had the opportunity to read all of the Subcommittee reports.

Then came the work of coordinating all the Subcommittee reports, eliminating differences or inconsistencies and grouping together all the recommendations and proposed model (or demonstration) projects. Dr. Marilyn Albert, Assistant Professor of Psychiatry and Neurology at Massachusetts General Hospital and Harvard Medical School, undertook the great responsibility for this assembly, coordination and editing, and several meetings of our Executive Board were devoted to the review and approval of the final documents. Dr. Sheila Clemon-Karp and Dr. Joan Hyde cooperated very effectively in this extensive process. These individuals provided enormous service to our Committee. The final meeting of the Full Committee approved the recommendations and proposals, following some changes, and subject to editing meetings.

Executive Board

The following individuals constitute the Executive Board. Secretary of the Executive Office of Elder Affairs Richard H. Rowland and Secretary of the Executive Office of Human Services Philip W. Johnston, who continuously supported our goals. Dr. Rowland attended our Committee meetings and gave enormous help. Secretary Johnston was unable to come to all meetings but was always represented.

Mrs. Charlotte Alintuck, a Vice-President of Massachusetts ADRDA, was Chairperson of the Subcommittee on Institutional Care. She has a long background in every facet of Alzheimer's Disease and follows the development of federal and state legislation and relevant policies and programs.

Ms. Donna Campbell, Clinical Coordinator for the Dementia Study Unit in the Geriatric Research Education and Clinic Center at the Veterans Administration Hospital in Bedford, whose special nursing unit has won acclaim for the quality of its care.

Warren Dahlin, Executive Director of South Shore Elder Services, served as Chairperson of the Subcommittee on Community-Based Care. He had a full career in the various aspects of home, community, day, and respite care and expertise in long term care.

Dr. Roger Hickler, Geriatrician, with rich experience, is involved daily with the medical care of Alzheimer's patients and with their families' problems: psychological, sociological and economic, as well as medical.

Dr. Robert Morris, Professor Emeritus of the Florence Heller Graduate School of Advanced Studies in Social Welfare at Brandeis University, an authority on health policy for the elderly, with profound wisdom.

Dr. F. Marott Sinex, President of the Massachusetts ADRDA and active at the national level of ADRDA, Microbiologist at the Boston University School of Medicine, an expert in the relationship between Alzheimer's Disease and Downs' Syndrome, with a full background in all the problems of Alzheimer's Disease.

Dr. Richard Tyler, Chief of Neurology at Brigham & Women's Hospital, with great experience in the medical care of dementia patients and the problems of their families.

Dr. Terrie Wetle, Assistant Professor of Health Policy at Harvard Medical School, supervisor of a number of research projects which relate to Alzheimer's patients and families and the cost of medical care.

Subcommittees

In addition to Mrs. Charlotte Alintuck (Institutional Care), Warren Dahlin (Community-Based Care) and Dr. F. Marott Sinex (Current Programs) who were members of the Executive Board; the other Subcommittee Chairpersons were:

Dr. David A. Drachman, Co-Director of the Massachusetts Alzheimer's Disease Center, funded by the National Institute on Aging, and Chief of Neurology at University of Massachusetts Medical School, chaired the Subcommittee on Research and Practice.

Jacob Getson, Vice-President of Massachusetts Blue Cross/Blue Shield, headed the Subcommittee on Finance and Insurance. He had the strong support of his assistant, Dr. Diane S. Piktialis.

Our Education Subcommittee was chaired by Thomas L. Goodgame, General Manager of WBZ-TV Channel 4. In Mr. Goodgame's absence, Dr. Joan Hyde represented and reported for the Subcommittee at Executive Board and General Committee meetings.

Ms. Sonia Boyajian chaired the Subcommittee on Families. Her personal experience enabled her and the many families represented on the Subcommittee to prepare a moving report.

Judge Mary Muse of the Suffolk Probate and Family Court, chaired the Legal Subcommittee. She, Senator Jack Backman, and I selected eight young lawyers and law teachers to assist in preparing a comprehensive report on legal issues.

The Alzheimer's Committee Report

At the meeting of the Executive Board on May 23, 1985, followed by the full Committee meeting, we approved the publication of this report with all the Subcommittee reports, the full Committee's recommendations and proposed demonstration projects, subject to editorial change by Dr. Albert, Dr. Clemon-Karp and me.

While both the Resolve and this report refer to Alzheimer's Disease, what this Committee wrote includes the words: "and Related Disorders." The estimated number of patients with Alzheimer's exceeds the number of those with Related Disorders. Physicians and support groups expressly treat them as one "group" of patients; both have many of the same or similar symptoms and the same end; complete loss of cognitive powers. In addition, many of the problems of victims of Alzheimer's Disease and Related Disorders and their families apply also to those elderly who need long term care.

This report contains a number of recommendations for evaluation and action by the Commonwealth, individuals and agencies.

One group, outside government, the medical and scientific community and the media, but working closely with all of them deserves special commendation. ADRDA gave extraordinary support to the activities of the Committee. We look to ADRDA for continuing advocacy and lobbying, information and educational programs, advice to the public on the needs of Alzheimer's Disease patients and families, and support of research.

Voluntary agencies, such as the constituent and beneficiary agencies of philanthropic organizations, like the United Way, United Community Planning Corporation, Catholic Charities, Combined Jewish Philanthropies, Hebrew Rehabilitation Center for the Aged, and others concerned with the frail

elderly and Alzheimer's patients should be encouraged to form, with ADRDA, an Alzheimer's coalition.

Thanks

As we conclude our current efforts, we owe a debt of gratitude to:

Governor Michael S. Dukakis who showed his confidence in us by our appointment and his continuing interest in our efforts and who only this week assured us that he will give our recommendations and proposals high priority; and to members of his office, including Catherine M. Dunham of Human Resources.

Secretary of the Executive Office of Elder Affairs, Richard H. Rowland and Secretary of the Executive Office of Human Services, Philip W. Johnston for their continuous support and help, personally and through their staffs. Their coordinating efforts, continuing into the future, will play a key role in the Commonwealth's help to Alzheimer's patients and their families.

Special thanks to Dr. Sheila Clemon-Karp of the Executive Office of Elder Affairs, our Staff Director, who was extraordinarily helpful, and to her effective staff: Maureen Barton, Eva Hester, Edward B. Kovar, Andrea Lehtonen, John McGrane, and Julie Tessler.

Our legislative members, Senators George Bachrach, Jack Backman and Edward L. Burke and Representatives A. Joseph DeNucci, Barbara E. Gray and Richard A. Voke, the President of the Senate, William M. Bulger, Speaker of the House of Representatives George Keverian and to all the members of both bodies for their expressed interest in our work, and in anticipation, for their support.

Dr. Marilyn Albert, who graciously undertook the difficult task of coordinating and editing this report, including its recommendations and proposals.


Dr. Joan Hyde for performing a wide variety of important services including coordinating the public hearings and filling in for various chairpersons of Subcommittees.

All the members of the Executive Board and Chairpersons of the Subcommittees, an exceptional collection of experts with a wide variety of talent.

The full Committee, deeply concerned with the problems of Alzheimer's patients and their families, faithful in attending meetings and articulate in expressing their views and devoted to the need to give all possible help through the federal and state governments, and through private sectors.

This report is by no means a final chapter. It is hopefully one step toward the goal of doing all in our power to help Alzheimer's patients and their families.

May 31, 1985



Lewis H. Weinstein, Chairman

INTRODUCTION

In the last decade, Alzheimer's Disease has become a serious societal and medical problem. As our population ages, more and more of us are reaching the age at which Alzheimer's Disease and related disorders reach epidemic proportions.

Although Alzheimer's Disease can strike people as young as 30, its prevalence increases with age, so that less than 1% of the citizens of Massachusetts between the ages of 40 and 60 now suffer from Alzheimer's Disease, 5% to 7% of those aged 60 to 80, and 20% to 30% of the people over 80 have Alzheimer's Disease and other dementing illnesses. Although good diagnosis and records have not been kept, we can estimate, based on epidemiological data, that approximately 40,000 Massachusetts citizens now suffer from Alzheimer's Disease, and another 30,000 from other forms of dementia.

If no cure is found by the year 2000, we project that the total number of Massachusetts citizens suffering from Alzheimer's Disease or a related disorders will exceed 100,000.

Alzheimer's Disease is not only a personal tragedy for those who are stricken and for their families and friends, it is also a very costly disease. It is estimated that half of all Massachusetts nursing home patients have some form of dementia. Neither Medicare nor private health insurance covers the costs of long term care for this or other chronic diseases. The burden of nursing home care alone for Massachusetts patients during 1984, is estimated at \$667,354,000. Twenty-five to thirty percent of this is paid for by individual families at great personal sacrifice, and often impoverishment. The rest is paid for, after the patient becomes indigent, by Medicaid. Under federal law, fifty percent of this is paid for directly out of the coffers of the Massachusetts State government. Total long term care expenditures in Massachusetts for 1984, including chronic hospitals, nursing and rest homes, and home health agencies, are estimated at \$1,026,660,000.

The fact that Alzheimer's Disease touches almost everyone is illustrated by the probability of personal involvement: if both of one's parents survive past 65, there is approximately one chance in three that their child will become responsible for the care of one or the other parent. As the number of elderly reaching age 65 exceeds the number of young people reaching maturity (as it did for the first time in 1984), fewer and fewer working people will be supporting more and more individuals subject to Alzheimer's Disease. These considerations create a time bomb, perilously close to its point of explosion.

Those who have examined the needs of patients and families affected by Alzheimer's Disease in the state of Massachusetts know that there is a need for a more comprehensive and coordinated system of care. Improvements are needed in all of the following areas:

- 1) Provision of information. Families of patients with Alzheimer's Disease need accurate, accessible information regarding the nature

of the disease process, health care professionals who are expert in the diagnosis and management of disease, community facilities that can provide assistance, institutions for those patients who can no longer be cared for at home, and legal and financial guidance.

- 2) Medical expertise. Accurate early diagnosis by physicians expert in the problems of dementia is necessary. Recognition of treatable dementing illness is crucial and highly cost effective. Once the diagnosis is made, there is a great need for continued medical management of problems such as incontinence, concurrent medical illness, and behavior problems.
- 3) Services for patients maintained at home. Respite care, day care, home care, and home health care services are critically needed in adequate quantity to enable families of patients with Alzheimer's Disease to maintain patients at home, and to sustain a reasonable existence for themselves and other members of the family. Legal advice, support groups and a variety of social services are needed as well.
- 4) Institutional care. Because all patients with Alzheimer's Disease who survive long enough eventually require total care, the majority end up in institutions. Adequately financed, insured, subsidized nursing home care is sorely needed for those with advanced dementing illness.

The Governor's Special Committee on Alzheimer's Disease feels that the Commonwealth must become more deeply engaged in a coordinated manner in the provision of solutions to these problems. It is clearly evident that the existing resources and the organization for their efficient utilization are inadequate in Massachusetts and require constructive orderly improvement.

The Committee on Alzheimer's Disease has addressed a broad variety of problems associated with Alzheimer's Disease and related disorders through a review of existing information and the testimony of individuals affected by, or dealing with, Alzheimer's Disease at every level: families of affected patients, health professionals, state officials dealing with public assistance programs, health insurance executives, nursing home managers, etc.

Subcommittees of the Committee on Alzheimer's Disease have reviewed as many facets of the problem as have appeared useful and practicable. As a consequence of these extensive deliberations, the Committee as a whole has derived a number of specific recommendations. Each recommendation addresses one or more of the problems identified above.

We recognize that an effort to deal with the problem of Alzheimer's Disease will be costly, and that there are many state functions that compete for fiscal priority. Nonetheless, we feel that there is an imperative need to come to grips with the problems engendered by Alzheimer's Disease and related disorders. The already existing scope of the problem, and its future rapid expansion, require that an effective, organized, and systematic approach be started at once. To this end we commend the following recommendations:

RECOMMENDATIONS OF THE GOVERNOR'S COMMITTEE ON ALZHEIMER'S DISEASE

Budgetary

1. The respite care system of the Executive Office of Elder Affairs should be expanded by 2 million dollars in fiscal year 1986 to provide additional respite care for patients with Alzheimer's Disease and related disorders. The type of respite services available should continue to include: homemaker/personal care, companion, home health aides, skilled nursing, social day care, adult day health, and short term institutional care. Services should continue to be available on a "sliding fee" scale.
2. At least four demonstration programs, funded by Requests For Proposals (RFP), should be developed in the field of dementing illness. Such programs would attempt to provide a more coordinated, systematic, and creative approach toward serving the patients and families who suffer from Alzheimer's Disease and related disorders. Since there is a lack of information about the most effective treatment modalities for these individuals, the demonstrations should explore a number of different models including: health and social service prototypes, institutional and community-related programs, academically and non-academically-related projects. The Long Term Care Work Group (a presently operating inter-agency task force) would oversee the development and evaluation of the demonstration programs and recommend funding (at a cost of no more than \$500,000 per program) for either the Executive Office of Elder Affairs or the Executive Office of Human Services to carry out the actual program planning, funding and evaluation. A staff person from the Office of Alzheimer's Information (see below) would be responsible for working with the Long Term Care Work Group to develop their recommendations.
3. An Office of Alzheimer's Information should be established within the Executive Office of Elder Affairs to oversee the dissemination of information to: the general public, family members, paid and volunteer caregivers, state and government employees, and health professionals. This office would oversee and implement the recommendations of the Special Task Force on Information and Referral for Alzheimer's Disease and related disorders. It would work with the Area Health Education Center (AHEC) to improve the education of health professionals. It would also assist the Long Term Care Work Group in developing and implementing its recommendations related to Alzheimer's Disease and related disorders. The Office of Alzheimer's Information should consist of no less than three staff members, for a total estimated cost of no less than \$85,000 per year.
4. Funds should be appropriated for the Department of Public Health to conduct a health interview survey to determine the number of patients in the Commonwealth with Alzheimer's Disease, their family status, their utilization of resources, and their ability to gain access to the health care system.

5. The Area Health Education Center should receive additional appropriations targeted for the training of health professionals in the area of Alzheimer's Disease and related disorders.
6. The Department of Public Health should be funded to develop education and training material for appropriate in-house and attending staffs of long term care facilities so that they are educated in "state of the art" drug therapy and other management techniques for patients with Alzheimer's Disease and related disorders.

Administrative

1. The Long Term Care Work Group should be directed to develop criteria for at least four demonstration programs in the field of dementing illness. Plans for soliciting, funding, and evaluating the demonstration programs should be provided to the legislature by February 1, 1986. Since the Long Term Care Work Group cannot actually carry out the plans developed by it for the issuance of RFPs or for detailed program planning and evaluation, the responsibility for this should be assigned to the Executive Office of Elder Affairs and the Executive Office of Human Services, as determined by the design of the demonstration programs. The Executive Office of Human Services would be responsible for institutional demonstration programs and the Executive Office of Elder Affairs would be responsible for community-based demonstration programs. Budgetary allocations would be made accordingly. The function of the Long Term Care Work Group should not, however, be limited to overseeing the demonstration programs, but should also include advice and consultation on other issues concerning Alzheimer's patients and their families.
2. A Special Task Force on Information and Referral (I & R) for Alzheimer's Disease and related disorders should be established for one year to evaluate and make recommendations for upgrading existing information and referral services. The activities of the task force should include designing a training program for I & R workers to enhance their ability to provide appropriate information and support. The task force should consist of representatives from existing information and referral systems, both governmental and private. The activities of the task force should be coordinated by the Office of Alzheimer's Information.
3. The Area Health Education Center program should be directed to pursue all appropriate avenues for improving professional education in regard to Alzheimer's Disease and related disorders. This should include: developing new continuing education programs in the area of Alzheimer's Disease and related disorders, encouraging existing programs to include more information concerning Alzheimer's Disease and related disorders, and working with medical schools to expand the training of new physicians in the area of dementing illness.
4. The Executive Office of Elder Affairs is encouraged to continue its efforts to improve the home care system's capabilities to serve the most frail in the community setting, including Alzheimer's patients most in need of services by virtue of their functional impairment.

This capability should include the training of home care staff and the development of new and specialized programs, including home management services (e.g., social workers, occupational therapists, and adaptive equipment) geared to family caregivers of Alzheimer's patients.

5. The purchase of service system in the Commonwealth should be reviewed by the Executive Office of Human Services and the Executive Office of Elder Affairs to insure adequate provision of professional services in community settings. There must be incentives to care for indigent Alzheimer's patients who lack supportive families.
6. There is a need to review and adjust current reimbursement schedules to take into account the special care needs of patients with Alzheimer's Disease and related disorders. Medicaid, Medicare, Blue Cross/Blue Shield, and other insurers, as well as the Rate Setting Commission and the Department of Public Health, should be mandated to work together: 1) to establish an appropriate policy to address this issue with respect to hospitals, nursing homes, adult day health programs and other providers, and 2) to adjust physician's and other provider's reimbursement rates so as to establish appropriate compensation for complex and time-consuming medical services, and avoid financial disincentives for provision of such services.
7. Since the Executive Office of Elder Affairs is mandated to provide service to individuals aged 60 and over, the care of Alzheimer's patients under the age of 60 is frequently neglected. The Executive Office of Human Services, though its Department of Social Services, should organize and provide service to Alzheimer's patients under 60 years of age.
8. The Governor should appoint a commission or committee to deal with legal issues of great concern to patients with Alzheimer's Disease and related disorders, such as: distribution of property and burden of care, trusts, guardianships, conservatorships, durable powers of attorney, living wills, the patient as a research subject, family participation in medical care and the administration of psychotropic medication and the jurisdiction of the Probate and Family Court to deal with these issues.
9. There should be a longer period of retroactive determination of disability for Alzheimer's Disease by the Social Security Administration. This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect disability payments if a diagnosis was made in a later stage of the illness. The Massachusetts Congressional delegation and the state agencies concerned with these issues should try to influence the Social Security Administration to implement this change.
10. State Licensing Board examinations for medical, nursing, and allied health professionals should include questions related to the recognition and differential diagnosis of the dementias (including Alzheimer's Disease), and to the management of patients with dementia.

Legislative

1. The Federal Government should create a Medicare, Part C program which would cover specified long term care services, both institutional and non-institutional. As a first step in a strategy to implement this recommendation, the Massachusetts Congressional Delegation should be asked to introduce legislation directing the Secretary of the Department of Health and Human Services to establish a Blue Ribbon Commission charged with developing a concrete Medicare reform plan within a specified period of time.
2. Private long term care insurance should be developed as a major component of long term care financing to provide choice to those who can afford it and who may not want to rely on public programs or who may want to purchase more flexible coverage. A State Commission to study the level of need for private long term care insurance, barriers blocking the development of such insurance, and strategies to encourage the development of such insurance should be established as proposed by House Bill 93.
3. A comprehensive financing strategy should encompass changes in tax policy, including credits to families supporting a family member with Alzheimer's Disease, in order to alleviate the burden on families. Mechanisms for protecting family assets should be developed. Several current Federal bills would reform tax policy to assist families in financing care of the chronically disabled, including those suffering from Alzheimer's Disease. These could be first steps in a national tax policy to address the needs of Alzheimer's patients and their families. The bills are: S.778, S.779, H.R.467, H.R.644, and H.R.723. These bills, as well as those before the Massachusetts legislature, allow exemptions or deductions for an elderly relative, regardless of health or care needs, usually specifying that the relative must be at least 75 years old. The bills would better serve the above stated purposes if they were amended so that eligibility is based upon age or on a diagnosis of dementia of the Alzheimer's type or a related disorder.

Private Sector

1. Private employers should permit a longer period of retroactive determination of disability for Alzheimer's Disease. This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect accumulated benefits if a diagnosis is made in a later stage of the illness.
2. Private industry, the state, health care providers, and professionals should collaborate to bring about the programmatic changes outlined in the Committee's report.
3. To insure that the recommendations of the Committee are brought to fruition, advocates must continue to actively work with the state government to achieve their goals.

POTENTIAL DEMONSTRATION PROGRAMS

- I. A demonstration adult day health program and/or adult social day care program should be established to permit families of moderately affected patients with Alzheimer's Disease to be maintained at home as long as possible. This program might include:
 - 1) programs of physical activity to help maintain the mobility of patients
 - 2) consultation from an experienced physician to provide guidance regarding the general health of the patients and the control of difficult behavior
 - 3) programs of mental stimulation to maximize the cognitive capacities of the patients
 - 4) counseling and therapeutic services for patients and their families to help them cope with the impact of Alzheimer's Disease
 - 5) the services of a trained social worker to assist families in gaining access to social services
 - 6) protected exits and outdoor exercise areas
- II. A demonstration program in a long term care facility should be established to develop state-of-the-art care for patients with Alzheimer's Disease and related disorders. This program should place an emphasis on a total care plan and innovative treatment methods, which might include:
 - 1) improved staff-to-patient ratios
 - 2) interdisciplinary diagnostic and behavioral evaluations
 - 3) careful monitoring of patients' pharmacological status
 - 4) physical security for patients while permitting maximum freedom of movement
 - 5) protected exercise areas to foster physical mobility
 - 6) provision for family member participation in the caregiving process in selected circumstances
 - 7) provision of family counseling services
 - 8) provision of short term respite care services
- III. A demonstration care-delivery and financing program should be developed to explore alternative cost-effective and care-efficient systems for caring for Alzheimer's patients. The design of this managed care demonstration program is similar to that used in HMOs and Social HMOs. This program might include:
 - 1) a financing strategy that is geographic in nature, with a fixed budget or capitated financing
 - 2) a wide variety of services so that the care that is most appropriate and least costly for patients can be provided
- IV. A demonstration program for the diagnosis and management of patients should be established. This program, operating out of a clinical center, would serve as an entry point for patients with Alzheimer's Disease and related disorders. It might include:
 - 1) a team approach to the diagnosis of Alzheimer's Disease, with individuals to provide neurological examination, psychiatric

evaluation and psychometric testing

- 2) social service support to guide patients and families in the range of appropriate medical and community resources

V. A demonstration program for home management services should be established. This program would include specialized rehabilitative, home management and consultative services to caregivers, which might include:

- 1) availability of disciplines such as occupational, physical and speech therapy
- 2) nutrition services
- 3) adaptive equipment (e.g., handrails, lifts, transfer boards, individually designed drinking cups, etc.)

MEMBERSHIP

THE GOVERNOR'S COMMITTEE ON ALZHEIMER'S DISEASE

MR. LEWIS H. WEINSTEIN, CHAIR

DR. SHEILA CLEMON-KARP, STAFF DIRECTOR

Dr. Marilyn Albert
Departments of Psychiatry & Neurology
Massachusetts General Hospital

Ms. Charlotte Alintuck
Vice President, ADRDA

Commissioner Charles Atkins
Department of Public Welfare
Dr. Joanne Bluestone (Designee)

The Honorable George Bachrach
Massachusetts Senate

The Honorable Jack H. Backman
Chairman Human Services and
Elder Affairs Committee
Massachusetts Senate

Ms. Maureen Barton
Executive Office of Elder Affairs
(staff)

Ms. Sonia Boyajian
Watertown

The Honorable Edward L. Burke
Chairman Health Care Committee
Massachusetts Senate

Mr. Henry Burnett
Sturbridge

Dr. Mary J. K. Burres
Bourne Council on Aging

Commissioner James J. Callahan, Jr.
Department of Mental Health
Ms. Martha Dunn (designee)

Ms. Donna Campbell
Veterans Administration Hospital
Bedford

Ms. Jan Carey
Department of Social Services

Mr. Warren Dahlin, Executive Director
South Shore Elder Services

The Honorable A. Joseph DeNucci
Chairman Human Services and
Elder Affairs Committee
Massachusetts House of Representatives
Ms. Maura Recko (designee)

Mrs. Jean C. DeVeber
Stoughton

Dr. David A. Drachman
Department of Neurology
U/MASS Medical Center

Mr. Noel Early
Share Care Day Care

Mrs. Pat Eliot
Association of Massachusetts
Non-profit Homes for the Aging

Dr. Denis Evans
E. Boston Neighborhood Health Center

Ms. Linda Fitzgerald
Nursing Home Ombudsman
Council of Churches of Greater
Springfield

Mayor Raymond Flynn
Boston City Hall

Mr. Jake Getson, Vice President
Blue Cross/Blue Shield
Dr. Diane S. Piktialis (staff)

COMMITTEE ON ALZHEIMER'S DISEASE - PAGE 2

Mrs. Margorie Glassman
Family Service Association
Boston

Mr. Thomas Goodgame
Vice President and General Manager
WBZ-TV

The Honorable Barbara E. Gray
Massachusetts House of Representatives
Mr. George Harrington (designee)

Ms. Eva Hester
Executive Office of Elder Affairs
(staff)

Dr. Roger Hickler
Department of Gerontology
U/Mass Medical School

Dr. Joan Hyde
Executive Director, ADRDA

Secretary Philip Johnston
Executive Office of Human Services
Ms. Diane Mazonson (designee)

Ms. Adrienne Kefeyan
Belmont

Mr. Edward Kovar
Executive Office of Elder Affairs
(staff)

Mrs. Bella Krovitz
Executive Office of Elder Affairs
Citizens Advisory Committee

Dr. William Kvaraceus
Clark University

Ms. Lillian Lashua
Hudson

Mr. Joseph Lawlor
Nursing Home Ombudsman
North Easton

Ms. Andrea Lehtonen
Executive Office of Elder Affairs
(staff)

Dr. Don Lipsitt
Mount Auburn Hospital

Dr. Robert Master
Office of Long Term Care
Boston City Hospital

Mrs. Kathleen McCarthy
Westside Nursing Home

Mr. John McGrane
Executive Office of Elder Affairs
(staff)

Dr. Robert Morris
Heller School
Brandeis University

The Honorable Mary Muse
Suffolk Probate and Family Court

Mr. George Noble, Jr.
Weston

Ms. Louise Pepe
Melrose

Mr. Neil Robertson
Children's Hospital Medical Center

Secretary Richard H. Rowland
Executive Office of Elder Affairs

Mr. Olivia Saar-Nyhan
American Speech and Hearing Association
Andover

Dr. Thomas Sabin
Department of Neurology
Boston University Medical School

Dr. Dennis Selkoe
Department of Neurology
Brigham and Women's Hospital

Mr. Thomas Shaughnessy
Clinton

Dr. F. Marott Sinex
Department of Biochemistry
Boston University Medical School

Mr. Alan Solomont
Prescott House Nursing Home

Ms. Marie Stackpole
Social Service Association

Ms. Carolyn Talbourdet
North Shore Visiting Nurse Association

Commissioner Michael Taylor
Boston Commission of Affairs of the
Elderly
Deputy Commissioner Veronica Smith
(designee)

Ms. Julie Tessler
Executive Office of Elder Affairs
(staff)

Ms. Denise Thomas
Malden

Dr. H. Richard Tyler
Department of Neurology
Brigham And Women's Hospital

Ms. Jean Tyler
Executive Director
Alzheimer Support Group of Berkshire County

Ms. Marge Vallone
Springfield Council on Aging

The Honorable Richard Voke
Chairman, House Ways and Means Committee
Massachusetts House of Representatives
Mr. David Matteodo (designee)

Commissioner Bailus Walker
Department of Public Health
Mr. Roger Marks (designee)

Mrs. Jean Weatherbee
Andover

Dr. Terrie Wetle
Division of Health Policy &
Division on Aging
Harvard Medical School

